Kentucky Birth Surveillance Registry

# The *KBSR* Reporter

Winter 2001 The Newsletter of the Kentucky Birth Surveillance Program Vol. 2, Issue 1

***Dear Colleague:***

Welcome to the second issue of *The KBSR Reporter*. These are very exciting times in Kentucky for issues around birth defects and genetics. The Governor's Early Childhood Initiative included $3 million over the biennium for folic acid supplementation. All health departments in the state have received funding to provide education, counseling and supplementation to women of childbearing age. This strategy should result in a decrease in the number of children born each year in Kentucky with neural tube defects.

The Department for Public Health has also been successful in securing funding for a two-year grant for Kentucky Newborn Screening and Infrastructure Development. These funds will be utilized to develop integrated databases with genetic information and to develop a statewide genetics plan. More details are available in the article on page two.

The Kentucky Birth Surveillance Registry and the Genetics Program are teaming together to implement a "Physician Champion Network" in Kentucky. Health care providers were identified at birthing hospitals in Kentucky to attend an annual meeting that included speakers on a variety of topics related to genetics. The participants will advocate for the birth defects registry and genetic issues within their community. The first annual meeting was held November 10-11, 2000 at the Sheraton in Lexington, and the title of the conference was "Genetics Across the Lifespan". I am excited about the interest that partners showed at this program, and look forward to preparing Kentucky for the challenges ahead in these areas.

On behalf of Kentucky's children, thanks for all you do!!! Information about this program is available through the KBSR at (502) 564-2154.

Steve Davis, MD
Director, Division of Adult and Child Health
Kentucky Department for Public Health

***Did You Know....***

In an Average Week in Kentucky:

| | |
|---|---|
| **1,023** | Babies are born |
| **164** | Babies are born to teen mothers (ages 15-19) |
| **26** | Babies are born to mothers who receive late prenatal care or no prenatal care |
| **14** | Babies are born very low birthweight |
| **7** | Babies die before their first birthday |

Source: March of Dimes Perinatal Profiles, 2000 Edition

*In This Issue:*

# Genetics Corner

## Folic Acid: It May Prevent Anomalies Other Than NTDs

Bryan D. Hall, M.D., University of Kentucky,
Department of Pediatrics

Folic acid when taken by the pregnant mother will reduce the risk of her fetus having a neural tube defect. This is a proven fact (Iqbal MM:Pediatrics in Review 21(2):58-66, 2000). However, folic acid may also reduce the risk of recurrence of other birth defects including cleft lip with or without cleft palate (Tolarova M, Harris J: Teratology 51:71-78, 95, Czeizel AE:Brit Med J 306:1645-1648, 93). Czeizel AE et al (Teratology 53:345-351, 96) in a case control study showed a significant reduction in the frequency of neural tube defects, cardiovascular anomalies, cleft lip/cleft palate, and cleft palate alone in fetuses of mothers who took 2-3 mg daily of folic acid. Botto LD et al (Pediatrics 98(5):911-916, 96) in another case control study demonstrated a 43% reduction of conotruncal heart defects (e.g., tetralogy, truncus, d-transposition, right-sided aortic arch, double outlet right ventricle) when pregnant mothers took periconceptional multivitamins. Tolarova and Harris (Teratology 51:71-78, 95) noted a reduced recurrence in subsequent offspring of women who had had a previous child with cleft lip/cleft palate with the use of periconceptional multivitamins and folic acid supplementation.

In all the above studies the percentage of reduction of the defects varied from 43-75%. Further studies need to be done to confirm these findings and additional anomalies need to be studied. In any regard, folic acid, used periconceptionally, potentially offers an inexpensive, safe means of reducing the frequency of some of the most common birth defects. Data gathered from the KBSR will be an important adjunct in establishing accurate data relative to folic acid's overall role in preventing birth defects.

## Genetic Planning Grant Funded

Joyce M. Robl, MS, CGC

The Department for Public Health, Maternal and Child Health Branch has received a two-year grant entitled "Planning Grant for Kentucky Newborn Screening and Infrastructure Development" from the Health Resources and Services Administration. The two components of this grant are a "child health profile" and the development of a statewide genetics plan.

The "child health profile" component will integrate child health data from existing databases. Data fields with information specific to child health and specifically genetic information will be combined to allow for both population-based and individualized health data on all children in the state. This integration will allow for optimal program planning and policy development on children's health issues throughout Kentucky.

The second component of this grant involves the development of a state genetics plan. The amount of information that will be available from the Human Genome Project and the impact on all individuals requires that Kentucky be prepared for this information and that a plan for genetic issues be established. Some of the issues that will be addressed include access to services, education (both lay and professional), testing, adult issues, prevention, ethical, legal and social implications.

KBSR is Online!
Visit our web page at:
http://publichealth.state.ky.us/kbsr.htm or e-mail us at
kbsr@mail.state.ky.us

# Condition Highlight

## The Role of Diabetes in Fetal Malformations

John M. O'Brien, MD, Director, Perinatal Diagnostic Center, Central Baptist Hospital, Lexington, KY

We all know that a proper environment for a child to grow and learn is important in becoming a well-adjusted adult. Similarly, a proper environment is also essential for the unborn embryo or fetus to develop. This proper environment allows for cellular migration to occur normally during organogenesis and avoids birth defects. When the embryo is exposed to excesses, such as too much glucose, the potential exists for abnormalities. Women with diabetes mellitus, or high blood sugar, are at increased risk for having a child with a birth defect due to either an inadequate amount of insulin in their body or a resistance to insulin.

The classification of the diabetes mellitus in the mother, Type I (juvenile onset) or Type II (adult onset), does not matter to the developing fetus. What is known is that the higher the average blood sugar, the higher the risk of birth defects. This risk reaches odds of one in ten in women with the poorest blood sugar control. Even if a women is not formally diagnosed with diabetes, some studies show an increased risk for birth defects in women with only mild degrees of glucose intolerance. Therefore, it is important for every pregnant woman to stay away from diets high in concentrated sugars. Pregnant women should attempt to balance their diets with increased fibers and vegetables and not binge on cakes and candies.

Several types of malformations may result from excess blood sugar. In the nervous system, neural tube defects or spina bifida are known possibilities. Congenital heart defects and kidney abnormalities are also increased in diabetic patients. The most pathognomonic abnormality for diabetic embryopathy, however, is a condition called sirenomelia or caudal regression syndrome. This frequently fatal anomaly is seen 200 times more commonly in the offspring of women with diabetes than healthy women.

Without question, the most important aspect in the care of a pregnant patient who is diabetic is prevention. Prior to conceiving, a woman with diabetes, or any woman who may have a blood sugar problem, should monitor their blood sugar. High glucose values should be aggressively controlled with the help of a doctor. This control creates the optimal environment for her child to develop from the start. If a woman with diabetes has blood sugars close to the normal range, the risk for birth defects can be reduced to 3-4%, close to the 2.5-3% in the general population. Adjusting blood sugar prior to pregnancy is the essential step, as waiting until after pregnancy is evident to the women, is frequently too late and a problem may already exist.

Women with diabetes, like all women considering pregnancy, should also be on vitamin supplementation prior to the start of a pregnancy. This will ensure adequate folic acid and other nutrients are present for organ formation. Supplemental Vitamin E may also help reduce the risk of birth defects in diabetic patients if taken in moderate doses. I recommend 200 to 400 international units per day to patients with diabetes considering pregnancy.

Once a patient with diabetes is pregnant, careful ultrasound examinations are necessary to evaluate the fetus for any signs of birth defects and to watch the growth of the child. Referral to a Maternal-Fetal medicine specialist should be considered at least once during the pregnancy. With close observation and adequate preparation, the vast majority of these patients can have normal, healthy newborns which is the goal of every parent.

# Kentucky Folic Acid Partnership

Susan Brown, RN, State Coordinator

Greetings from the Kentucky Folic Acid Partnership! Since our kick-off last September we have grown from nineteen agencies/organizations to forty-five. Our membership includes 55 individual members who represent even larger numbers of people working within a particular agency. This makes the task of "spreading the news" across the state much easier. It really does take ALL of us to make a Partnership!

Membership is open to any agency or individual who would like to join. Helpful qualities are passion, dependability, and creativity! Making a commitment to attend meetings (at least three per year) is also an added plus! Our goal is to reach all women of child-bearing age in Kentucky with the folic acid message…"taking 400 micrograms of folic acid daily before and during pregnancy can decrease neural tube defects by 70% !" The next step after awareness is providing the folic acid for women to take daily and ensuring their compliance. The Governor's Initiative signed into law (HB 706) on April 4, 2000 can make this happen. Three million dollars is budgeted for the Folic Acid Campaign over the next two years! How exciting! There has never been a more ENTICING time to jump on board then now! If you are already a member but haven't been to a meeting in awhile… come and join us February 1st at the State Lab Building in Frankfort from 10:00 till 12:30 Eastern Daylight Time. Those who aren't members as yet but are interested may contact Susan Brown, State Folic Acid Campaign Coordinator at 270-781-8039 extension 181 or email

Sbrownfolicacidco@yahoo.com

Come aboard and make things happen!

MEMBERS AS OF DECEMBER, 2000

Department for Public Health
March of Dimes
Spina Bifida Association of Kentucky
Barren River District Health Department
Commission for Children with Special Health Care Needs
Shriner's Hospital
Kentucky Chapter of OB-GYN
Kosair Charities Pediatric Center
Kentucky Perinatal Association
University of Louisville
Montgomery County Health Department
Kentucky Pediatric Society
University of Kentucky
Kentucky Chapter American Academy of Family Physicians
Humana
red7e Advertising
Two Roads Communication, Inc.
Ad Club of Louisville
Lexington-Fayette County Health Department
Lincoln Trail District Health Department
Bourbon County Health Department
Northern Kentucky Independent District Health Department
Green River District Health Department
Kentucky Developmental Disabilities Council
North Central District Health Department
Cumberland Valley District Health Department
Franklin County Health Department
Three Rivers District Health Department
Madison County Health Department
Clark County Health Department
Bluegrass Family Health
Passport Health Plan
Anthem Blue Cross & Blue Shield
Indiana University SE Campus
Central Baptist Hospital
St. Elizabeth Medical Center
WEDCO District Health Department
Gateway District Health Department
KY River District Health Department
Jefferson County Health Department
Anderson County Health Department
Lake Cumberland District Health Department
AHEC-HETC
FIVCO District Health Department
Little Sandy District Health Department

## A Word from the March of Dimes

Katrina Adams, Program Services Director,
Greater Kentucky Chapter March of Dimes

The January/February 2000 issue of Teratology featured an article entitled "Collecting and Interpreting Birth Defects Surveillance Data by Hispanic Ethnicity: A Comparative Study," which was co-authored by the staff of March of Dimes Perinatal Data Center. This study highlights the importance of collecting information on Hispanic ethnicity in birth defects surveillance programs. Such information is important because Hispanic infants have higher rates of many birth defects, including neural tube defects, and many programs currently do not include Hispanic ethnicity identifiers. Other articles in the journal discuss topics such as neural tube defects surveillance; genetic susceptibility to birth defects; assessment of clinical genetics services; and integrating birth defects surveillance in maternal and child health on the state level.

The Greater Kentucky Chapter of the March of Dimes collaborated with Horizon Research International to complete a Folic Acid Awareness Benchmark Study in Warren and Pike Counties. A telephone survey was conducted among 300 women in Warren County and 300 women in Pike County, Kentucky who were 18 to 45 years of age. The objective was to benchmark levels of awareness of B-vitamin folic acid and several kinds of behavior related to taking vitamins, multivitamins, and folic acid, specifically. Overall, both counties exhibited substantial reported awareness of B-vitamin folic acid. Awareness levels in Warren County were somewhat higher than awareness levels in Pike County.

The School of Nursing at Indiana University has utilized a March of Dimes grant to prepare a folic acid presentation educating women about folic acid and encouraging the use of a supplement or multivitamin daily prior to conception. ISU held a folic acid workshop on April 10, 2000.

## Focus: Getting the "B" Attitude in Pike Co.

Sarah Chaffin, RN, Pike County Health Department

Prior to the beginning of the folic acid campaign in our county in November 1999, Horizon Research International conducted a benchmark phone survey in our county of 300 childbearing women ages 14 to 45 years. The primary sources of awareness about folic acid and its benefits were print media (mostly magazines), a health care provider (most commonly a physician), and broadcast media (most commonly television). The Pike County Folic Acid Campaign is utilizing the innovative ideas of its professional and community partners in conjunction with the March of Dimes Getting the "B" Attitude materials to increase the number of childbearing women consuming 400 mcg of folic acid daily. Listed below are a few of the ways in which this message is being provided.

- **Professional**

Physicians and their staff encourage childbearing patients to make a personal commitment to taking folic acid supplements and improving dietary intake of folate.

Pharmacists display the "B" Attitude literature with bottles of folic acid supplements to help customers connect the message with the vitamin.

- **Community**

Avon Representatives explain and give to their customers the "B" Attitude flyer

Cabinet for Families and Children caseworkers utilize the "B" Attitude materials for all childbearing women applying for a medical card

Shops specializing in bridal registration for gifts, china, and wedding gowns are presenting the bride-to-be with the message

County clerk offices are presenting couples the flyers when they apply for a marriage license.

Our community partners are finding simple, successful solutions to improve the lives for our future children. Folic acid is one such solution. *Get the "B" attitude*—it's easy and it works.

# Database Update

Sandy Fawbush R.N.

The KBSR has a new contract with the Kentucky Hospital Association/Compdata for collection of hospital data. A contractual programmer is working with the KBSR to evaluate the existing system and make modifications to the KBSR database system. The proposed modifications will facilitate more accurate data collection and lead to production of an annual report. The current data process requires coordination with a number of resources to collect information for analysis.

**Modifications to Database:**

1. Replace the mainframe matching process with an equivalent Access matching process designed to work directly with the KBSR Access system. This will allow users of KBSR to make modifications to data directly in the KBSR system.
2. Establish the birth of a child through inclusion of Newborn Screening information into KBSR. This will establish the birth of a child prior to receiving the birth information through vital statistics. This will improve the overall timeliness of matching and reporting capabilities of KBSR and provide more timely ascertainment of appropriate referrals into services such as early intervention.
3. Maintain a non-modifiable KBSR identifier for each child in the KBSR system. This will assure data is unduplicated.
4. Incorporate the Neural Tube Defect (NTD) registry into KBSR to take advantage of its reporting capabilities.
5. Create online reports to assess the KBSR population in a more timely fashion.
6. Retain unmatched UB92 records for potential identification through medical records abstraction.
7. Improve the quality of error reports for suspect or incomplete information.

These modifications will be completed so that reports generated by KBSR will be directly compatible with the Early Childhood Development Data Repository (FOCUS).

Ultimate goals of KBSR include: analysis of the possible causes of birth defects and disabling conditions; facilitate the development of preventative strategies to reduce the incidence of these defects; and ensure that eligible children are referred for appropriate services in a timely manner. These goals are reliant on a data system that is efficient and timely.

## Resources

**PiNK (Parent information Network of Kentucky, Inc.)**

* A statewide, family-driven, family-centered peer support and information network focused on being an umbrella of all resources that are available to the parents/families of Kentucky
* Our goal is to provide parent to parent support, information and networking opportunities for Kentucky families who have children with any disability, chronic illness or special health care needs. We also provide training, technical assistance and referral for families and professionals who work with children with special needs.
* We are the state chapter for Family Voices which is a national grassroots network of families and friends speaking on behalf of children with special health care needs

*Contact: Veronica Brown, P.O. Box 5266, Louisville, KY 40255-0266*
*(502) 479-PiNK (7465) or families in KY can call 1-877-611-PiNK (7465),*
*website: www.KYP2P.org,*
*e-mail: PiNK@kyp2p.org*

# Birth Defects on the Internet

***State Birth Defects Registries***

**California**
**(www.cbdmp.org)**
This site contains a program overview, registry data and research findings. There is also information about cluster investigations, information on selected birth defects and publications.

**Florida**
**(www.doh.state.fl.us)**
This site provides a program overview, general information on birth defects, information for professionals, and internet links.

**Texas**
**(www.tdh.state.tx.us/tbdmd/index.htm)**
A program overview, publications and cluster investigation information are available on this site. There is also a fact sheet about the Texas Birth Defects Research Center.

**North Carolina**
**(**www.schs.state.nc.us/SCHS/about/programs/bdmp.html**)**
This site contains a program overview and current activites as well as contacts at the state level.

***Birth Defects-Related Sites***

**National Birth Defects Prevention Network**
**(www.nbdpn.org/NBDPN)**
This site provides information about the Network, and provides links to state birth defect registries, newsletters and other news.

**On-line Mendelian Inheritance in Man (OMIM)**
**(www3.ncbi.nlm.nih.gov/Omim/searchomim.html)**
Provides a search of OMIM. Just enter a keyword, and the listing from Mendelian Inheritance in Man can be reviewed.

**Genetic Alliance**
**(www.geneticalliance.org)**
This site searches for support groups. There is also information available on resources, publications, and public policy issues.

**Gene Clinics**
**(www.geneclinics.org)**
This site contains information related to the diagnosis, management and genetic counseling of individuals and families with specific inherited disorders.

# KBSR Reportable Codes

| | |
|---|---|
| All Congenital Anomalies | 740 –759 |
| *Examples:* | |
| Microcephaly | 742.1 |
| Macrocephaly | 742.4 |
| Upper GI Anomalies | 750 |
| Lower GI Anomalies | 756.7 |
| Metabolic/Storage Disorders | 270-279* |
| *Excluding codes 274, 276, 278 | |
| Dwarfism, Not Elsewhere Classified | 259.4 |
| Hereditary Hemolytic Anemia | 282 |
| Neurologic Disorders of Brain and Cord | 334 |
| Cerebral Palsy | 343 |
| Umbilical Hernia | 553.1 |
| Teratogen (noxious influences) | 760.7 |
| Fetal Alcohol Syndrome | 760.71 |
| Narcotics | 760.72 |
| Hallucinogenic Agents | 760.73 |
| Cocaine | 760.75 |
| Small for Gestational Age | 764 |
| Hemolytic Disease of Newborn | 773 |
| Infant of Diabetic Mother | 775 |
| Seizures | 779* |
| *To allow for coding error | 780.3 |
| Failure to Thrive | 783.4 |

# Calendar—Upcoming Conferences

January 29-31,2001

## National Birth Defects Prevention Network 4th Annual Meeting

"Advances and Opportunities for Birth Defects Surveillance, Research and Prevention"
San Antonio, TX

Late July, 2001

## Infant-Toddler Conference

Lexington, KY
Information: Linda Wainscott or Jo Comely (502) 564-7722

September 18-21, 2001

## 44th Annual Maternal and Child Health Conference

Galt House, Louisville, KY
Information: (502) 564-2154

The ***KBSR Reporter*** is published twice a year by the Kentucky Department for Public Health, Division of Adult and Child Health.

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